



# Psychosocial well-being in postpartum women with congenital heart disease

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**Background:** Improved treatment options for congenital heart disease (CHD) lead to a growing number of women with CHD at reproductive age. Due to physical and psychological burden, pregnancies in women with CHD often count for high-risk. Resulting emotional distress can adversely impact pregnancy, motherhood and fetal health. The present study aims to retrospectively investigate mental outcomes and indices of adjustment in women with CHD before, during and after pregnancy. The novel concept of illness identity is applied to explain how patients experience and integrate their CHD into their identities.

**Methods:** Patient-reported outcome measures on mental functioning and illness identity were assessed in a sample of 121 postpartum women with CHD [mean age: 42.7±9.2 (range, 27–81) years] at the German Heart Centre Munich between August and November 2021 in a cross-sectional design. Descriptive analyses, correlations and linear regression models were calculated.

**Results:** Retrospectively assessed prevalence of emotional distress before giving birth was high (47.0%) and peaked shortly after childbirth in terms of elevated symptoms of postpartum depression and trauma. During the course of maternity, emotional distress decreased significantly (24.1%,  $P < 0.001$ ). Overall, postpartum women demonstrated high scores in functional illness identity states (i.e., acceptance and enrichment) and low scores in dysfunctional states (i.e., rejection and engulfment). CHD severity was not directly associated with mental outcomes ( $P > 0.05$ ), whereas maternal cardiovascular risk, according to the WHO classification, was significantly associated with a higher prevalence of postpartum trauma ( $t = 2.485$ ,  $P = 0.015$ ).

**Conclusions:** Postpartum mental health problems, such as (postpartum) depression, anxiety, and posttraumatic stress can become a serious burden which might be detrimental to the mother's well-being and her infant's development. Present findings emphasise the urgent need for a holistic approach focusing on pregnant women with CHD starting at the prepartum stage to prevent adverse consequences and promote maternal well-being. Illness identity might become an important target construct for clinical practice as it may positively and enduringly influence mental well-being of pregnant women with CHD.

**Keywords:** Adults with congenital heart disease (ACHD); illness identity; postpartum; pregnancy

Submitted Apr 28, 2022. Accepted for publication Jul 21, 2022.

doi: 10.21037/cdt-22-213

**View this article at:** <https://dx.doi.org/10.21037/cdt-22-213>

## Introduction

Congenital heart defects (CHD) count among the most common types of birth defects (1). More than 1.35–1.5 million children are born with any type of CHD. Due to improvements and progress in congenital cardiology management and heart surgery, 97% of all CHD patients, in developed countries, reach adulthood (2).

The increasing number of adults with congenital heart disease (ACHD) and improved options for treatment lead to a growing number of women with CHD at reproductive age who would like to get pregnant. Due to cardiovascular adaptations and hemodynamic changes during pregnancy, pregnancies in women with CHD often count as high-risk pregnancies. High-risk pregnancies are known to be accompanied by a higher prevalence of depression, anxiety or posttraumatic stress disorder (PTSD) related to traumatic pregnancy or birth experience (3–5). If left undetected and untreated, poor mental health might have serious consequences on a woman's well-being, her parenting ability and, consequently, her infant's cognitive and emotional development (6,7).

To date, this is the first study to systematically assess pregnancy related mental health outcomes in women with CHD. The aim of this study was: (I) to depict the mental status of postpartum women with CHD in terms of emotional distress and quality of life (QOL), (II) to explore the concept of illness identity, a construct indicating how chronically ill patients integrate their experienced illness into their identity and how they deal with their illness (8), in this patient population and (III) to investigate possible medical predictors (CHD and pregnancy related) associated with postpartum mental outcomes. We present the following article in accordance with the STROBE reporting checklist (available at <https://cdt.amegroups.com/article/view/10.21037/cdt-22-213/rc>).

## Methods

### Population

The present retrospective cross-sectional study was carried out at the German Heart Centre Munich. Inclusion criteria were: (I) a confirmed diagnosis of CHD, (II) participant age 18 years or older, (III) the presence of one or more pregnancies in the past, (IV) sufficient physical, cognitive and language capabilities to complete self-reported questionnaires. Women who were currently pregnant were excluded from the study population.

### Data collection

Participants were recruited between August and November 2021 using three different strategies to generate maximum response: (I) women were approached during waiting time at the ambulatory department of CHD and paediatric cardiology, (II) questionnaires were handed out to eligible in-patients by the head nurse and (III) due to the ongoing COVID-19 pandemic, a postal recruitment strategy was implemented to increase opportunities for remote/non-hospital-based research visits. All eligible patients were asked to complete the surveys during their visit. The study was conducted in accordance with the Declaration of Helsinki (as revised in 2013). The study was approved by the ethics board of the Technical University of Munich (No. 399/21S) and informed consent was taken from all individual participants.

### Measures

The following domains were measured: (I) sociodemographic variables, (II) pregnancy- and birth related factors, (III) emotional distress and (IV) illness identity. All outcomes were assessed using standardized questionnaires. For the measurement of emotional distress, three different questionnaires were used: the Hospital Anxiety and Depression Scale (HADS) (9), the Edinburgh Postpartum Depression Scale (EPDS) (10) and the Impact of Event Scale Revised (IES-R) (11). Quality of life was assessed by using the EQ-5D-5L (12). Illness Identity was measured with the Illness Identity Questionnaire (IIQ) (8). Additionally, participants filled in a questionnaire providing personal information. Variables concerning emotional distress were measured retrospectively for three different time points: (I) before giving birth (self-generated questionnaire), (II) during early motherhood (self-generated questionnaire, EPDS, IES-R) and (III) today (HADS, EQ-5D-5L, IIQ). “Before giving birth” combines the time prior to pregnancy as well as the time during pregnancy. “Early motherhood” was defined as the postpartum period, i.e., the first six months after childbirth (13). General emotional distress was also assessed “after giving birth”, meaning the time from childbirth until today. All questionnaires referred to the most recent pregnancy only. Clinical information related to the CHD were extracted from the patient's medical records.

All CHD were classified depending on their severity into three pathoanatomic groups, four groups according to

**Table 1** Sociodemographic variables of the study population

Variables (N=121)	Values
Age, years, mean $\pm$ SD [range]	42.7 $\pm$ 9.2 [27–81]
Marital status, n (%)	
In partnership	114 (94.2)
Single	1 (0.8)
Separated	2 (1.7)
Divorced	3 (2.5)
Widowed	1 (0.8)
Level of school education, n (%)	
No schooling completed	1 (0.8)
Primary school degree	23 (19.0)
Secondary school degree	41 (33.9)
General university entrance qualification	52 (43.0)
Other	4 (3.3)
Professional qualification (n=115), n (%)	
No professional degree completed	2 (1.7)
Still in educational training	1 (0.9)
Vocational training degree	70 (60.9)
Polytechnic degree	13 (11.3)
University degree	26 (22.6)
Other	3 (2.6)
Number of children (n=119), mean $\pm$ SD [range]	1.8 $\pm$ 0.7 [1–4]

pathologic physiology and clinical condition according to the classification of Stout *et al.* (1). Additionally, all patients were classified regarding their maternal cardiovascular risk during pregnancy in accordance to the WHO classification into five different groups (14).

### Statistical analysis

All calculations were performed using SPSS Statistics 28.0 (IBM Inc., Armonk, NY, USA). Descriptive analysis was used to calculate measurements of central tendency and distribution. As both outcome variables for mental functioning before and after childbirth were dichotomous, Wilcoxon test was performed to compare emotional distress before and during to emotional distress after childbirth. After testing for normal distribution using the Shapiro-Wilk test, non-parametric tests were applied. For the

assessment of associations between medical parameters and psychological functioning and illness identity, the Kruskal-Wallis test and Bonferroni post-hoc testing was used. In addition, the Spearman-rank correlation was used to detect possible associations. To gain more insight into group differences, unpaired *t*-tests were applied to look at between-group differences for special groups. Linear regression models were used for a better understanding of associations. To compare women with one child with women with more than one child, Mann-Whitney-U tests were used. All occurring P values and tests for significance were performed two-sided. Statistical significance was indicated by a P value <0.05.

## Results

### Participant characteristics

A total of 85 questionnaires was distributed in person at the outpatient and inpatient clinic of the German Heart Center Munich, of which 65 were returned (response rate 76%). Additionally, 90 questionnaires were sent out via mail, of which 57 were sent back (response rate 63%, total response rate of in person and postal recruitment 69%). One questionnaire was missing personal data and was therefore excluded. In some cases, not all questionnaires were filled in by the patients completely. Whenever this was the case, it is indicated in the results. In total, 121 participants were included in this study. The mean age of the study population was 42.7 $\pm$ 9.2 (range, 27–81) years. On average, women had two children with a maximum of four children and the time period between the most recent pregnancy and the time of investigation was 10.68 $\pm$ 10.47 (range, 0–51) years (see *Table 1*). *Table 2* depicts a classification of participants with respect to their CHD according to (I) pathologic anatomy, physiology, and clinical condition and (II) the WHO guidelines for risk classification of pregnancies in women with heart disease.

### Mental outcomes and illness identity in postpartum women with CHD

To assess emotional distress, different descriptive dimensions were measured. In total, 64 women (n=102; 62.7%), were worried to transmit their heart condition to their child. Of these 64 women, 11 (17.5%) reported to be influenced by this fear in their desire to become pregnant. Of 118 women, 89 (75.4%) were attending an antenatal

**Table 2** Clinical parameters and classification of the study cohort according to maternal cardiovascular risk (WHO classification) (14) and disease severity (1)

Variables (N=121)	Values
Cyanosis, n (%)	
Acyanotic	121 (100.0)
Cyanotic	0 (0.0)
Anatomy classification (n=120), n (%)	
I	21 (17.5)
II	62 (51.7)
III	26 (21.7)
Other	11 (9.2)
Physiology classification (n=120), n (%)	
A	47 (39.2)
B	36 (30.0)
C	35 (39.2)
D	0 (0.0)
Other	2 (1.7)
ACHD AP classification (n=120), n (%)	
IA	16 (13.3)
IB	1 (0.8)
IC	3 (2.5)
ID	0 (0.0)
IIA	21 (17.5)
IIB	23 (19.2)
IIC	18 (15.0)
IID	0 (0.0)
IIIA	7 (5.8)
IIIB	8 (6.7)
IIIC	11 (9.2)
IIID	0 (0.0)
Other	12 (10.0)
WHO pregnancy risk classification (n=120), n (%)	
I	19 (15.8)
II	23 (19.2)
II-III	38 (31.7)
III	32 (26.7)
IV	8 (6.7)

**Table 2** (continued)**Table 2** (continued)

Variables (N=121)	Values
Mechanical valve, n (%)	6 (5.0)
Homograft, n (%)	9 (7.5)
Systemic right ventricle, n (%)	17 (14.2)
Pacer, n (%)	10 (8.3)
ICD, n (%)	2 (1.7)
Fontan circulation, n (%)	0 (0.0)
Heritable thoracic aortic disease (%)	10 (8.3)
Birth method (n=118), n (%)	
Natural birth	57 (48.3)
Assisted birth	10 (8.5)
Planned C-Section	26 (22.0)
Unplanned C-Section	25 (21.2)
History of miscarriage (n=116), n (%)	
Yes	38 (32.8)
No	78 (67.2)

WHO, World Health Organization; ACHD AP, Classification of Adults with Congenital Heart Disease according to anatomy and physiology of the heart defect; ICD, Implantable Cardioverter Defibrillator; C-Section, Caesarean Section; Other, Patients who could not be classified according to the provided classification systems.

class. Values of emotional distress before and after birth are presented in *Table 3*. Women showed significantly less emotional distress after giving birth than before ( $Z=-4.226$ ,  $P<0.001$ ).

In total, 39 (32.2%) women presented symptoms of postpartum depression as indicated by a mean EPDS score of  $7.65\pm 5.95$  (range, 0–27). Of all women, 32 (26.4%) were identified as suffering from a mild form of PTSD, 22 (18.2%) presented a score higher than 33 and could be therefore classified as having a moderate PTSD according to the suggested cut-off values by the IES-R. The total mean for the IES-R scale was  $17.28\pm 16.60$  (range, 0–81).

The HADS total score demonstrated a mean of  $8.93\pm 6.44$  (range, 0–26), which was in the range of low overall distress. According to suggested cut-off values, 27 women (22.3%) were identified as highly emotional distressed, 18 (14.9%) as depressed and 30 (24.8%) as suffering from anxiety.

Mean QOL (EQ-5D index) was  $0.92\pm 0.13$  (range,

0.51–1).

Taken together, dimensions of emotional distress directly after pregnancy (i.e., PTSD and postpartum depression) were high in women with CHD. In contrast to that, current mental outcomes (i.e., emotional distress in general, depression and anxiety) were significantly lower than before pregnancy and QOL was high.

Concerning illness identity, participants overall showed high scores in acceptance [4.28±0.95 (range, 1–5)] and enrichment [3.46±1.16 (range, 1–5)] and low scores in rejection [1.85±0.92 (range, 1–4.40)] and engulfment

[1.52±0.64 (range, 1–3.38)]. Accordingly, adaptive illness identity states were higher than maladaptive states in postpartum women with CHD.

**Mental outcomes and illness identity in postpartum women with CHD in relation to medical parameters**

Only for maternal cardiovascular risk during pregnancy according to the WHO classification and IES-R a statistically significant correlation was detected ( $r_s=0.209$ ,  $P=0.031$ ). For all other dimensions of emotional distress and all three classification systems, no significant correlations were found (Table 4).

Regarding possible associations between classes of disease severity, maternal cardiovascular risk and dimensions of emotional distress, no significant group differences were found. However, for maternal cardiovascular risk and IES-R, a trend can be seen [ $H_{(4)}=7.993$ ,  $P=0.092$ ] (Table 5). A post-hoc test showed significant differences regarding the IES-R score between WHO maternal risk Class I and IV ( $Z=-2.518$ ,  $P=0.012$ ).

A linear regression model revealed an effect of WHO classification of maternal cardiovascular risk on IES-R score [ $F_{(1, 105)}=6.177$ ,  $P=0.015$ ] with higher maternal risk classes showing higher IES-R scores ( $t=2.485$ ,  $P=0.015$ ). Still, model fit was low with  $R^2=0.056$ .

Looking at pregnancy related variables, there was a significant correlation between method of birth and EPDS ( $P=0.038$ ). Though, testing for differences between the methods of birth showed no significant results ( $P=0.204$ ). For all other dimensions, no significant correlations were found ( $P>0.05$ ). All correlation coefficients are presented in Table 6. Testing women with one child against women with more than one child showed no significant differences regarding any of the measured outcome variables ( $P>0.05$ ).

**Table 3** Mental outcomes in women with congenital heart disease before and after childbirth

Dimension	Before childbirth	After childbirth
Emotional distress	n=117	n=116
	55 (47.0%)	28 (24.1%)
Depression	n=55	n=28
	33 (60.0%)	20 (71.4%)
Anxiety	n=55	n=28
	26 (47.3%)	14 (50.0%)
Eating disorders	n=55	n=28
	5 (9.1%)	2 (7.1%)
Psychotic events	n=55	n=28
	4 (7.3%)	0 (0.0%)
Addiction	n=55	n=28
	1 (1.8%)	0 (0.0%)
Psychological treatment	n=55	n=27
	40 (72.7%)	9 (33.3%)
Psychotropic drugs	n=55	-
	17 (31.5%)	

**Table 4** Correlation between classes of disease severity, maternal cardiovascular risk, and dimensions of emotional distress today (HADS) and in the postpartum period (IES-R and EPDS)

Classification	HADS			IES-R	EPDS
	Total	Anxiety	Depression		
Anatomy classification	-0.034	0.026	-0.096	0.129	0.155
Physiology classification	0.074	0.045	0.080	0.151	0.075
WHO classification	0.006	0.022	0.005	0.209*	0.148

\*,  $P<0.05$ . HADS, Hospital Anxiety and Depression Scale; IES-R, Impact of Event Scale Revised; EPDS, Edinburgh Postpartum Depression Scale; WHO, World Health Organization.



**Table 5** Associations between classes of disease severity, maternal cardiovascular risk and dimensions of emotional distress today (HADS) and in the postpartum period (IES-R and EPDS)

Classification	HADS			IES-R	EPDS
	Total	Anxiety	Depression		
Anatomy classification (P value)	0.259	0.457	0.246	0.401	0.285
Physiology classification (P value)	0.237	0.267	0.278	0.215	0.276
WHO classification (P value)	0.890	0.886	0.958	0.092	0.360

HADS, Hospital Anxiety and Depression Scale; IES-R, Impact of Event Scale Revised; EPDS, Edinburgh Postpartum Depression Scale; WHO, World Health Organization.

**Table 6** Correlations between pregnancy related variables and dimensions of emotional distress today (HADS) and in the postpartum period (IES-R and EPDS)

Variables	HADS			IES-R	EPDS
	Total	Anxiety	Depression		
Fear of transmitting CHD	0.114	0.181	0.069	0.191	0.133
Method of birth	0.082	-0.038	0.187	0.086	0.203*
Miscarriage	0.080	0.112	0.043	-0.014	-0.004
Antenatal class	-0.045	-0.21	-0.018	-0.086	-0.079

\*,  $P < 0.05$ . HADS, Hospital Anxiety and Depression Scale; IES-R, Impact of Event Scale Revised; EPDS, Edinburgh Postpartum Depression Scale; CHD, congenital heart defects.

## Discussion

To the best of our knowledge, this is the first quantitative study to retrospectively examine mental outcomes in postpartum women with CHD. The present study revealed several clinically important trends: First, women with CHD experienced a high burden of emotional distress before and during pregnancy. Immediately after giving birth, emotional distress in terms of postpartum depression was also elevated. In the long-term, emotional distress decreased and patients currently reported beneficial mental outcomes. Second, the findings suggest that the majority of postpartum women with CHD were able to successfully integrate their illness into their self-concept which was currently reflected by positive illness identity states (i.e., acceptance and enrichment). Third, higher maternal cardiovascular risk during pregnancy was correlated with an increased risk of postpartum PTSD.

To date, there is still insufficient knowledge on mental outcomes in postpartum women with CHD. In light of the high emotional burden before, during and immediately after pregnancy, women with CHD require timely interdisciplinary support to cope with pregnancy-related

fears and challenges. Present findings further suggest that women with higher maternal cardiovascular risk during pregnancy present a greater risk for postpartum depression and trauma. Screening this group of high-risk women will alert clinicians to the need for additional follow-up and referral to psychosocial support services. Remarkably, the overall process of pregnancy, childbirth, and motherhood might have a profound beneficial impact on a woman's self-concept. This might therefore become an important target variable for clinical practice as it may positively and enduringly influence mental well-being in women with CHD.

### *Mental outcomes in postpartum women with CHD*

Various dimensions of emotional distress were investigated. Emotional distress was reported to be high before and during pregnancy. Further, more than one third of all women were classified as postpartum depressive right after giving birth. QOL was good and comparable to the general ACHD population (15) as well as to German population norms (16). The prevalence of depression and anxiety prevalence is comparable to previously reported findings in

ACHD (17) and higher than levels in the general German population (18). Elevated levels of emotional distress in high-risk pregnancies have already been reported in various studies (3-5). There might be various reasons: first, women with CHD often fear that they could never become a mother (19). Additionally, results of the present study show that women with CHD are highly concerned about transmitting their heart defect to their newborn. In this context, Nakamura *et al.* revealed that some women might feel guilty in regard to possible risks for their own or their child's health or even for not being able to start a family with their partner. Flocco *et al.* identified the fear of dying during pregnancy or birth as another burdensome factor for women with CHD (20). Even though women feel that having a child is part of a normal life and have a strong desire to become a mother, some women experienced the way towards pregnancy as highly burdensome. Judgmental behaviour of others might also contribute to high levels of emotional distress before pregnancy: some women felt a lot of pressure to conceive or, in contrast, felt to be judged as being selfish as they wanted to become a mother. Overall, women seem to undergo an extremely difficult way towards the decision to become pregnant and due to the uncertainty of their prognosis (21).

Elevated depression and anxiety levels before and during pregnancy count as a major risk factor for postpartum depression (22-26). It has been shown that postpartum depression does not only have a negative impact on the mother's health but also influences the child's interpersonal functioning, quality of attachment and a raised level of emotional disturbance (6,7). In this regard the findings of the present study are alarming. Prevalence of postpartum depression was almost double as high as in the general German population (32.2% *vs.* 18%) (27). It was equal to postpartum depression in high-risk pregnancies (28). Hence, the results of our study support the urgent need for psychological assessment for women with CHD as they seem to be especially at risk for postpartum depression.

Women with CHD did not show high levels of general emotional distress at the time they participated in the study. On the contrary, emotional distress since postpartum period was even lower than in the general ACHD population (17). In addition, QOL was good. According to Ngu *et al.*, women with CHD have a strong desire to become a mother for various personal, cultural or religious reasons (29). One of the most important causes of this desire is, however, probably the wish to live a normal life. Women with CHD perceive their motherhood as a victory over their disease.

They seem to look at pregnancy as one of the greatest battles of their life and therefore are proud and relieved to have won this fight (20). Furthermore, parenthood can lead to an increase in the sense of meaning and purpose (30). The presence of meaning and purpose can act as a protective factor for emotional distress and lead to higher life satisfaction (31).

Birth-related trauma was comparable to other high-risk pregnancies (32). Possible reasons for birth-related trauma in women with CHD will be discussed in the discussion parts regarding medical parameters.

### *Illness identity in postpartum women with CHD*

Within the present study, most postpartum women with CHD successfully integrated their CHD into their self-concepts as indicated by higher scores for "acceptance" and "enrichment" as compared to "engulfment" and "rejection". This patient population demonstrated even higher scores in "acceptance" and "enrichment" and even lower scores in "engulfment" and "rejection" than the general ACHD population investigated by Andonian *et al.* and Van Bulck *et al.* (33,34).

According to the qualitative study of Flocco *et al.*, becoming a mother can lead to better acceptance of the women's CHD (20). Acceptance means to be aware of the illness and not letting it intrude all areas of life (8). Overcoming the challenge of pregnancy might lead to a better acceptance of their heart condition, as women with CHD now see themselves as mothers and no longer as heart-sick women. This could possibly even enable enrichment, which has been defined as benefitting from one's illness. Remarkably, the intense experience of one's illness which might be enhanced by undergoing pregnancy and motherhood was described as a major prerequisite for enrichment in the literature (8). This might be the case before and during pregnancy, as women with CHD have to face their condition inevitably. Postpartum women described their successful pregnancy as a victory and as one of the hardest challenges they had to face. After pregnancy, women seem to feel stronger than before and might have gained strength from this challenge (20).

In their qualitative study Ngu *et al.* found, that women with severe heart conditions demonstrated a tendency to downplay their condition before pregnancy (29). This might be due to anxiety and worries of not being able to become a mother. The rejection or downplay of one's condition might go alongside with elevated levels of anxiety and depression

before giving birth. In contrast, high levels in acceptance and enrichment have been associated with lower prevalence of emotional distress (8,33). This protective impact of illness identity could also be a possible explanation of the good mental functioning in postpartum women in this study. So far, illness identity seems to be a stable construct within one person (34). Longitudinal research is required to investigate changes of illness identity throughout pregnancy and motherhood. Based on present findings, illness identity might become an important target variable for psychosocial interventions (35).

### *Mental outcomes and illness identity in postpartum women with CHD in relation to medical parameters*

Higher maternal cardiovascular risk during pregnancy due to the CHD and therefore indirectly also CHD severity was associated with higher risk for pregnancy- and birth-related PTSD. Regarding other mental parameters, no associations between maternal risk during pregnancy and disease severity have been found in this study. Furthermore, method of birth showed significant correlation with postpartum depression, but further statistical investigation revealed no group differences. Miscarriages, the fear of transmitting the heart disease to the unborn child and the attendance of an antenatal class were not associated with any of the emotional distress dimensions. The increased risk for postpartum PTSD in women with higher pregnancy risk and therefore more complex CHD can be explained by different factors. In general, studies demonstrate higher prevalence of postpartum PTSD in women with high-risk pregnancies (36). However, up to now it remains unclear what the main driver for PTSD might be—the demands of CHD, the associated medical events or the constant accompanying anxiety. In this context, Shlomi Polachek *et al.* found that those women who were more anxious about giving birth were more likely to develop postpartum PTSD (37). Women with a higher maternal cardiovascular risk, due to a more complex CHD, are potentially more afraid of childbirth than women with lower risk.

### *Limitations*

This study is the first to investigate long-term mental outcomes and the novel concept of illness identity in postpartum women with CHD. A representative sample of participants was enrolled in one of the largest and leading centers for ACHD in Germany. The present study displays

a remarkably high response rate and reflects a diverse study sample covering various types of CHD. Additionally, CHD were classified according to different classification systems and clinical variables such as structural complexity, physiological complexity, treatment status and maternal cardiovascular risk during pregnancy were assessed. Various indices of mental functioning were retrospectively assessed at several timepoints in a cross-sectional manner (throughout pregnancy and early motherhood) and therefore reveal some clinically important trends. However, this study also entails some limitations and results should therefore be interpreted with caution.

First, the present study was designed cross-sectional which does not allow any conclusions about directions of effect. For the investigation of causality of effect, longitudinal research is needed. Present findings provide strong indication for assessing psychological variables at several timepoints before, during and after pregnancy in a prospective design.

Second, most question items and psychological measures (i.e., postpartum depression and postpartum PTSD) were of retrospective nature. As some women were pregnant years ago, this entails great possibility of the risk of recall bias. Still, studies have shown that women remember pregnancy and childbirth very accurately, even over 20 years later (38). Additionally, medical procedures changed extremely during the last decades. Therefore, comparability between pregnancies now and pregnancies years ago might be limited. Due to medical advances, women with a more complex CHD are now able to become pregnant and experience motherhood. Previously, a medium to complex CHD led to a higher likelihood of complication during pregnancy and might have therefore created a higher level of emotional distress.

Third, another possible limitation is caused by the rather small sample size. This leads to small numbers of participants in some of the classification groups and therefore to less powerful options in statistical analysis. Additionally, the number of patients per classification systems varies widely. Furthermore, it should be noted that there were no patients with Fontan-circulation, cyanosis, single-ventricle disease or patients in group D according to the pathophysiological classification.

Fourth, all data collection tools reported measurements based on patient-reported data. All results are therefore susceptible to response bias. By assuring patients a strict pseudonymization of the surveys, this bias was minimized. In addition, women were asked to fill out the questionnaire



alone and not in attendance of their partner. Responses were not shared with their physician.

Fifth, statistical analysis was only performed for questionnaires after a woman's last pregnancy. Mental functioning after all other pregnancies was not considered. However, this limitation was addressed by testing women with one child against women with more children. Analysis of previous pregnancies has to be done in the future and was also part of the data collection.

## Conclusions

Due to medical and technological advances, there is an increasing number of women with CHD who reach reproductive age with the desire to get pregnant. The present study reveals evidence that depression, anxiety and PTSD can become a serious burden before and throughout pregnancy, which might be detrimental to the woman's welfare. Illness identity might become an important target construct for clinical practice as it may positively and enduringly influence mental well-being in women with CHD. Present findings emphasize the urgent need for a holistic women-centered approach providing appropriate interventions right at the prepartum stage to prevent adverse consequences and promote maternal and neonatal well-being.

## Acknowledgments

This research work was carried out on behalf of the Fördergemeinschaft Deutsche Kinderherzen e.V.

*Funding:* This work was supported by the Fördergemeinschaft Deutsche Kinderherzen e.V.

## Footnote

*Provenance and Peer Review:* This article was commissioned by the editorial office, *Cardiovascular Diagnosis and Therapy* for the series "Current Management Aspects in Adult Congenital Heart Disease (ACHD): Part V". The article has undergone external peer review.

*Reporting Checklist:* The authors have completed the STROBE reporting checklist. Available at <https://cdt.amegroupp.com/article/view/10.21037/cdt-22-213/rc>

*Conflicts of Interest:* All authors have completed the ICMJE uniform disclosure form (available at <https://cdt.amegroupp.com>).

[com/article/view/10.21037/cdt-22-213/coif](https://cdt.amegroupp.com/article/view/10.21037/cdt-22-213/coif)). The series "Current Management Aspects in Adult Congenital Heart Disease (ACHD): Part V" was commissioned by the editorial office without any funding or sponsorship. AF, SF, HK, NN report support received from Fördergemeinschaft Deutsche Kinderherzzentren e.V. Harald Kaemmerer served as an unpaid guest editor of the series. The authors have no other conflicts of interest to declare

*Ethical Statement:* The authors are accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved. The study was conducted in accordance with the Declaration of Helsinki (as revised in 2013). The study was approved by the ethics board of the Technical University of Munich (No. 399/21S) and written informed consent was obtained from all participating patients before the start of documentation. The study was registered at the Deutsches Register Klinischer Studien (DRKS00025868).

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**Cite this article as:** Freiberger A, Beckmann J, Freilinger S, Kaemmerer H, Huber M, Nagdyman N, Ewert P, Pieper L, Deppe C, Kuschel B, Andonian C. Psychosocial well-being in postpartum women with congenital heart disease. *Cardiovasc Diagn Ther* 2022;12(4):389-399. doi: 10.21037/cdt-22-213